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Early Hearing Detection and Intervention-Pediatric Audiology Links to Services EHDI-PALS: Building a National Facility Database

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Abstract

Objectives—To create a searchable web-based national audiology facility directory using a standardized survey, so parents and providers could identify which facilities had capacity to provide appropriate services based on child's age.

Design—An Early Hearing Detection and Intervention-Pediatric Audiology Links to Services expert panel was convened to create a survey to collect audiology facility information. Professional practice documents were reviewed, a survey was designed to collect pertinent test protocols of each audiology facility, and a standard of care template was created to cross-check survey answers. Audiology facility information across the United States was collected and compiled into a directory structured and displayed in an interactive website, ehdipals.org.

Results—Since November 7, 2012, to May 21, 2016, over 1000 facilities have completed the survey and become listed in the Early Hearing Detection and Intervention-Pediatric Audiology Links to Services directory. The site has registered 10,759 unique visitors, 151,981 page views, and 9134 unique searches from consumers. User feedback has been positive overall.

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Conclusion—A searchable, web-based facility directory has proven useful to consumers as a tool to help them differentiate whether a facility was set up to test newborns versus young children. Use of a preprogrammed standard of practice template to cross-check survey answers was also shown to be a practical aid.

Keywords

Early hearing detection and intervention; Facility search; Facility survey; Website

INTRODUCTION

In 1990, one of the goals of Healthy People 2000, the nation's health promotion and disease prevention agenda, was "to reduce the average age at which children with significant hearing impairment are identified to no more than 12 months old" (Mauk & Behrens 1993; U.S. Department of Health and Human Services, Public Health Service, 1990). Universal newborn hearing screening was demonstrated as feasible by Vohr et al. (2000) It was also demonstrated by the same authors that permanent childhood hearing loss could be identified as early as 3.5 months (Vohr et al. 1998). It was also feasible to identify at risk children for hearing loss at 8 to 12 years of age (Widen et al. 2000) Representative James Walsh of New York introduced the Newborn Infant Hearing Screening and Intervention Act of 1999 to encourage states to implement universal newborn hearing screening. Through this legislation, funds were appropriated for the Centers for Disease Control and Prevention (CDC) and Maternal Child Health Bureau to provide grants to states to develop a state-based Early Hearing Detection and Intervention (EHDI) program and a data system for tracking and surveillance purposes. In 2009, the Act was reauthorized.

Established in late 1969, the Joint Committee on Infant Hearing (JCIH) was composed of representatives from multiple national professional organizations. Committee members were expanded to include consumer advocacy organizations. The Committee was charged with a twofold responsibility: first, to make recommendations concerning the early identification of children with, or at-risk, for hearing loss, and second, newborn hearing screening. Among other items addressed, the most current Joint Committee on Infant Hearing (2007) Position Statement clarified the purpose of an EHDI tracking and surveillance system:

1. "States should implement data management and tracking systems as part of an integrated child health information system to monitor the quality of EHDI services and provide recommendations for improving systems of care." (p.899)
2. "An effective link between health and education professionals is needed to ensure successful transition and to determine outcomes of children with hearing loss for planning and establishing public health policy." (p.900.)

The CDC developed a survey and began collecting state-based newborn hearing tracking and surveillance data in 2007. Data collected included information about the receipt of services in accordance with the EHDI 1-3-6 goals (hearing screening before 1 month of age, diagnostic audiologic evaluation before 3 months of age for infants who do not pass the newborn hearing screening, and enrollment of infants identified with hearing loss in early intervention services before 6 months of age) directly from the state EHDI programs (Curry

& Gaffney 2010). The rate of newborns screened has increased steadily. Among the 49 states that contributed EHDI data in 2005, an estimated 94.2% of newborns were screened. By 2013, the 55 states and territories that contributed data reported that 97.2% of newborns were documented as having received a hearing screen. The diagnostic rate has seen a slower increase. In 2004, estimated data contributed by 41 states indicated that only 48.7% of newborns who failed the newborn hearing screening received a confirmation diagnostic test for the presence or absence of hearing loss. By 2013, the reported diagnostic follow-up had improved to 56.9%. This still left a sizable percentage 32.2% ($n = 17,160$) of infants' whose hearing status was unknown, either due to loss to follow-up or loss to documentation (Centers for Disease Control and Prevention, National Center on Birth Defect and Developmental Disabilities 2013). Loss to documentation includes infants who may have received a diagnosis but the result has not been reported to the EHDI program.

Access to Pediatric Audiology Services

Finding diagnostic audiologic and follow-up services for infants and young children can be challenging for parents and health care professionals. While some states have directories of diagnostic audiologic centers for parents, others do not. For those with directories, inclusion criteria varies widely, and other important aspects of care (e.g., on site otolaryngologists or on site interpreters) may be unclear. In some regions of the country, particularly rural areas with small populations, there is often a dearth of facilities that can provide appropriate audiological care for infants. As a result, some families have to travel farther for care or, when available, use teleaudiology services. The type of third party payment that a facility is willing to accept also affects access to care, e.g. if Medicaid is not accepted, parents might have to travel farther to find one that does, or decide not to get the needed care at all.

A potential contributing factor to difficulty in identifying a pediatric audiology facility is a lack of an official definition or requirement to be considered a pediatric audiologist. In pediatric medicine, the official term "pediatrician" implies the provider is proficient with newborns and children of all ages. However, an audiologists proficient in testing 8-year-olds, but not newborn infants, can be called a "pediatric audiologist," whereas many who go by the official term of "audiologist" may be proficient with children of all ages. This lack of official definition of pediatric audiologist creates confusion and is a potential impediment to parents finding a qualified audiologist or appropriate facility. An area with seemingly rich distribution of pediatric audiologists may in reality lack qualified pediatric providers who can effectively evaluate newborns and infants. Knowing the age group that an audiology facility is equipped to evaluate is of vital importance but is often not clear to parents, especially those with a newborn or infant.

In 2009, the CDC EHDI team reviewed audiology directories that state EHDI programs used to make referrals and whether a directory was publicly accessible. Forty-three states and territories compiled a list of audiology facilities. Of those, one was not accessible to the public and of the other 42 publicly accessible lists only 6 differentiated infant diagnostic centers from centers that provided diagnostic services for older children (Chung et al. 2010). With this information as a baseline, the following questions drove development of a

standardized approach to developing a consumer-friendly directory of resources for parents of children seeking pediatric audiology services:

Was it possible to develop a survey that can capture all the audiologic services offered by a facility for infants and young children?

If types of services from a facility were collected, was it possible to present the information in a searchable web-based format so that consumers, both parents and providers, could identify which facility had the capacity to provide appropriate services for infants and young children?

MATERIALS AND METHODS

To systematically capture all audiology services from a facility, a national facility survey had to be designed and constructed, using a consensus approach by a committee of experts in the field of pediatric audiology care. The CDC EHDI team convened an expert panel for the entire duration of the project that included state EHDI program coordinators and parents, ensuring regional differences in care process could be brought to light during the survey design and that parents' need were addressed. See Appendix A (Supplemental Digital Content 1, <http://links.lww.com/EANDH/A338>) for the project advisory committee and workgroup members' names and affiliations. The advisory committee was referred to as the Early Hearing Detection and Intervention-Pediatric Audiology Links to Services (EHDI-PALS) committee. The committee further delineated several objectives and necessary steps to realize the project after two in-person meetings:

Development of a facility survey inclusive of all aspects of audiologic services for an infant who had failed a hearing screen and for a child up to 5 years of age;

Development of an online website portal easily navigable by all intended users;

User testing on the facility survey and website.

Survey Development

The workgroup agreed on several characteristics, the facility survey must have in order that the data collected would be useful for intended users. First, the survey must only be directed at facilities, not providers. That meant that one survey would represent one facility at a unique and distinct geographical location and a deduplication mechanism must be built into the survey process to remove multiple surveys completed by providers from the same facility. Second, it was agreed that all diagnostic service-related questions would be categorized by age groups: 0 to 6 months, 6 months to 3 years, and 3 to 5 years of age. These diagnostic age groups reflect a distinct change in the testing methods when newborns mature between age 6 and 7 months and another that occur when children are older than 3 years of age.

Audiology services provided by each facility must conform to standards of practice, which are not easily captured through a facility survey that might ask this question directly. The best method to verify if a facility has adopted current standards of practice and has the requisite equipment to support best practice is to perform a site visit, review test protocols

and results, but this was not feasible for either the state EHDI programs or the EHDI-PALS committee to undertake. A feasible alternative was to cross-check survey answers with current pediatric audiology standard of practices. Using this approach, the workgroup reviewed the professional practice documents of American Academy of Audiology (AAA), American Speech-Language and Hearing Association (ASHA), and the JCIH 2007 Position Statement to create a standard practice template for diagnostic and hearing aid fitting. The following guidelines were reviewed: Guidelines for the Audiologic Assessment of Children From Birth to 5 Years of Age (ASHA 2004), the Guidelines for Audiologists Providing Informational and Adjustment Counseling to Families of Infants and Young Children With Hearing Loss Birth to 5 Years of Age, (ASHA 2008), Roles, Knowledge, and Skills: Audiologists Providing Clinical Services to Infants and Young Children Birth to 5 Years of Age (ASHA 2006), the Pediatric Amplification protocol (AAA 2013), the Remote Microphone Hearing Assistance Technologies for Children and Youth from Birth to 21 Years (AAA 2018). A diagnostic practice template was created for the three age groups: birth to 6 months, 7 months to 3 years, and 3 to 5 years. Fitting a hearing aid was not age specific, as current standard practice was consistent for all age groups. Both the diagnostic and hearing aid fitting templates were integrated into the survey to auto compare survey answers to standard practice, thereby assessing if a facility's reported processes were consistent with current standard practices. If answers matched the standard of care templates for birth to 6 months, 7 months to 3 years, and 3 to 5 years, the facility was identified as being able to offer a particular audiologic service for that specific age group.

The survey was beta-tested by six audiologists recruited by committee members from diverse clinical settings (public school, university, large medical centers, and privately owned practices). The second survey draft was tested by another group of audiologists. Two hundred and three audiologists recruited seven state EHDI programs tested the second survey draft.

Development of an Online Website

The facility information collected from the survey was structured and displayed in a consumer-friendly and searchable website, www.ehdipals.org. The website has been hosted by the Center for Research and Evaluation at the University of Maine. The Center continues to provide programming needs for the web-site. In an effort to meet health literacy levels of consumers, technical terms not easily understood were replaced by terms easier to understand. For example, "audiologic test" was replaced by "hearing test." If the literacy level of certain terms could not be lowered, an explanation of the term was displayed when a cursor was placed over the term. The search page was designed, tested, and reviewed by 8 parents who had newborns and children with hearing loss. Search parameters were based on what the consumer had entered for the age of the child, the types of services needed, and zip code of residence. Facilities that offered the requested service for the selected age group were displayed on a map based on proximity to the zip code of residence. To ensure that each facility's information remained up-to-date, an annual email alert was programmed to remind the facility contact person to return to ehdipals.org to review their survey answers.

The EHDI-PALS committee reached a consensus to use website traffic to determine whether or not the directory was valuable to consumers. The website has been programmed to track the Internet Protocol addresses to measure the number of total visitors to the website (including unique and return visitors), and the number of page views by the visitors. To measure the number of times visitors searched for audiology facilities in the directory, each click of the search button was counted. The EHDI-PALS website went live on November 7, 2012.

RESULTS

The 68-question EHDI-PALS Facility Survey was finalized by the workgroup and approved by the Federal Office of Management and Budget (#0920-0955). It was made available online at the <http://www.ehdipals.org> website. The 68-question survey composed of questions along the following categories:

1. Names of all audiologists providing services to children under 5 years of age
2. Type of facility (e.g., hospital facility, public school, or privately owned facility, etc.)
3. Facility name, address, contact information, and hours of operation
4. Types of services offered by the facility: diagnostic, hearing aid fitting, cochlear implant, and vestibular evaluation
5. The processes adopted for electrophysiologic and behavioral diagnostic tests
6. Hearing aid fitting verification and validation processes
7. Number of children under 5 years of age diagnosed and managed in the past year
8. Types of audiologic services available through remote telepractice technology and the telepractice set up
9. Other types of medical services (e.g., neurology, genetics, etc.) available within the facility or health system
10. Types of payment accepted
11. Availability of interpreter services for non-English speaking families
12. Knowledge on reporting the diagnostic test results to the state EHDI program
13. How often and what type of diagnostic test results were reported to the state EHDI program
14. Reasons for infrequent reporting to the state EHDI program.

The survey was disseminated to approximately 2200 audiologists through newsletters and e-announcements sent by AAA, ASHA, and the National Center for Hearing Assessment and Management. While the number of facilities reached was unknown, because all three organizations organized their member database by the name and e-mail contact of each audiologist rather than the place of work, as of May 21, 2016, over 1000 facilities from all

50 states, 2 territories, and the District of Columbia had been listed in the EHDI-PALS directory. The growth in facility enrollment is shown in Figure 1.

Facility Deduplication

All survey respondents were asked to enter the facility zip code at the beginning of the survey. All other facilities that had already completed the survey, and that had the same zip code, were then displayed. If the respondents were unable to find their facility on the list, they could proceed to create a username and password and then begin the survey. If the respondent did see their facility, they could click the link for it, after which they would be prompted to enter their username and password they had previously assigned for themselves. This had proven to be effective in preventing multiple personnel from the same facility completing the survey. To date (as of May, 2016), only 10 facilities out of over 1000 facilities had duplicate survey entries, which were subsequently resolved.

Cross-Checking Survey Responses

Both the diagnostic and hearing aid fitting templates were integrated into the survey to auto compare survey answers to standard practice when respondents were completing the survey. If answers matched the standard of care template for a specific age group, a facility service summary which summarized the types of services the facility was able to offer for consumers was displayed at survey completion. See Figure 2 for a screen shot of a facility service summary.

Overall Website Traffic

Since going live on November 7, 2012, as of May 21, 2016, the site has registered 10,759 unique visitors, 151,981 page views, and 9134 unique searches. Figure 3 displays the growth in page views and unique searches from November 2012 to May 2016. The website traffic averaged 30 to 40 new visitors each month.

DISCUSSION

The first dissemination and promotion of the EHDI-PALS facility survey to audiologists was in October of 2012. The web-site went live on November 7, 2012. By January 4, 2013, the date of a second promotion, 466 facilities had completed the survey and were listed in the EHDI-PALS directory. By the time of the third promotion on August 9, 2014, 432 more facilities were listed. As of May 21, 2016, an additional 111 facilities had completed the survey and successfully listed in the directory.

Visitors to the website also increased steadily. Since going live through August 6, 2014, website pages were viewed 75,125 times, and 4001 facility searches were made. Between August 7, 2014, and January 29, 2015, page views increased by 28,768 times and searches increased by an additional 901 times. From January 30, 2015, to May 21, 2016, pages viewed increased by 48,088 times and searches by 4232 times.

The EHDI-PALS committee did not specifically promote the EHDI-PALS directory to parents, but many state EHDI programs did. For example, Virginia, Louisiana, Nevada,

Idaho, and Pennsylvania EHDI programs have placed the EHDI-PALS.org link on their state websites.

EHDI-PALS has addressed a long known need to provide up-to-date and consistent information and access to clinicians, EHDI coordinators, and parents seeking pediatric audiological care (Muñoz et al. 2011). This project has demonstrated that a web-based national pediatric audiology facility searchable directory is useful for consumers.

Both parents and providers' feedback has been positive. Excerpts of some of the feedback from:

Physicians:

"Thanks - it's an awesome resource!!" (June 2, 2013)

"Congratulations on opening the door to the EHDI-PALS website. It is an impressive effort." (April 27, 2013)

Parents:

"This site is so extremely useful. I could have used it a year ago.

Everything looks great and there were no broken links." (March 2013)

"...wished there had been something like this when my child was diagnosed...it would have made it so much easier" (March 2013)

"Wish this was available when my daughter was born. How are you going to get this into the hands of parents (promotion)? You should make a brochure that we can handout at support groups. What if my child is older than 5, will this still work?" (March 2013)

Comparing survey answers with a standard practice template also proved feasible as evidenced by audiologists' feedback. The most frequently asked question by audiologists was why their facility was not displayed for diagnostic services for a certain age group or for hearing aid dispensing services. To address this and to facilitate audiologists cross-checking their own practice with the current standards, the project advisory committee condensed and summarized key standards from the AAA, ASHA, and the JCIH 2007 Position Statement into one document and posted it on the EHDI-PALS website.

The high usage rate (151,981 page views) since going live indicated that the site was utilized by consumers. Among the number of page views to date, 9134 were specifically for the facility search page. Since 10,759 were unique visitors, this suggested that consumers returned to EHDI-PALS.org more than once. EHDI-PALS.org is useful for consumers as evidenced by the high usage rate and the number of facilities captured. Displaying these audiologic services for facilities can be a helpful tool for consumers searching for the right services for children of a specific age.

Ongoing promotion of the website continues to be a need and a priority. Promotion to state EHDI program staff is of key importance because State EHDI program staff are uniquely positioned to assist parents connecting with pediatric audiology facilities. Five state EHDI

programs have placed the EHDI-PALS.org link on their state websites to increase visibility of EHDI-PALS. The committee also designed search tools for program staff who assist parents in accessing audiological services, such as the ability to search by types of services or by geographic region. EHDI program staff can access these specific search tools after an account has been set up in the EHDI-PALS. Since the introduction of these search tools 1 year ago, as of December 14, 2016, 42 state EHDI program staff have accounts in EHDI-PALS. In total, they performed 2617 facility searches. Although this number appears promising, it is too early to assess the impact of these promotional attempts. Ongoing efforts to make these tools available to state EHDI program staff, parents, and clinicians continue to be explored.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

All authors assisted in drafting the survey, the website design, resource compilation, critically revised the manuscript, and approved the final version. W.C. is the lead on the EHDI-PALS project. She directed and coordinated the committee. In addition, W.C. conceptualized the project. K.B. tested the survey. A.O. disseminated the survey. C.M. programmed the website.

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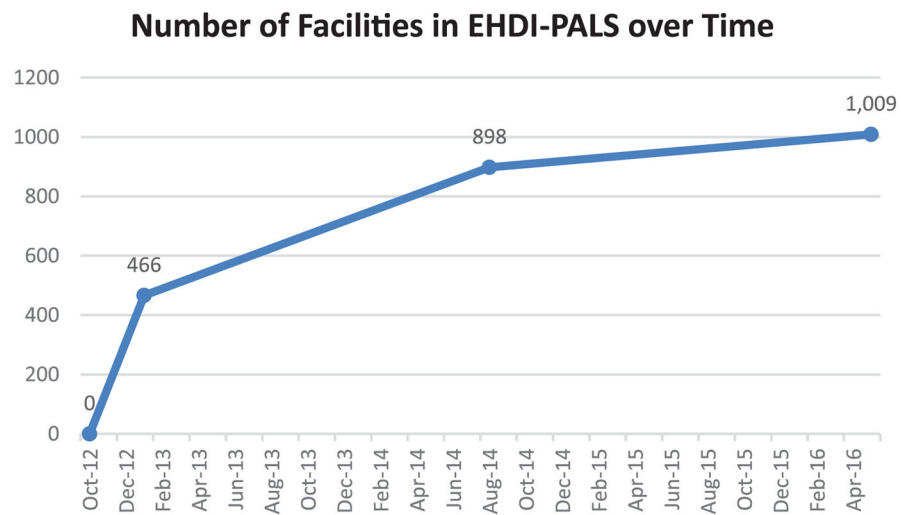


Fig. 1. Number of facilities captured in Early Hearing Detection and Intervention-Pediatric Audiology Links to Services over time.

Audiological evaluation from birth up to 6 months of age	<input type="checkbox"/>
Sedated audiological evaluation from birth up to 6 months of age	<input type="checkbox"/>
Audiological evaluation from 6 months of age up to 3 years of age	<input checked="" type="checkbox"/>
Sedated audiological evaluation from 6 months of age up to 3 years of age	<input type="checkbox"/>
Audiological evaluation from 3 years of age up to 5 years of age	<input checked="" type="checkbox"/>
Sedated audiological evaluation from 3 years of age up to 5 years of age	<input type="checkbox"/>
Hearing aid dispensing facility from birth up to 6 months of age	<input checked="" type="checkbox"/>
Hearing aid dispensing facility from 6 months of age up to 3 years of age	<input checked="" type="checkbox"/>
Hearing aid dispensing facility from 3 years of age up to 5 years of age	<input checked="" type="checkbox"/>
New earmold impressions from birth up to 3 years of age	<input checked="" type="checkbox"/>
New earmold impressions from 3 years of age up to 5 years of age	<input checked="" type="checkbox"/>
Cochlear Implant services for children	<input type="checkbox"/>
Vestibular services for children	<input type="checkbox"/>
Tele-practice service available	<input type="checkbox"/>

Fig. 2.

Screen shot of a facility service summary (source <http://www.ehdipals.org>).

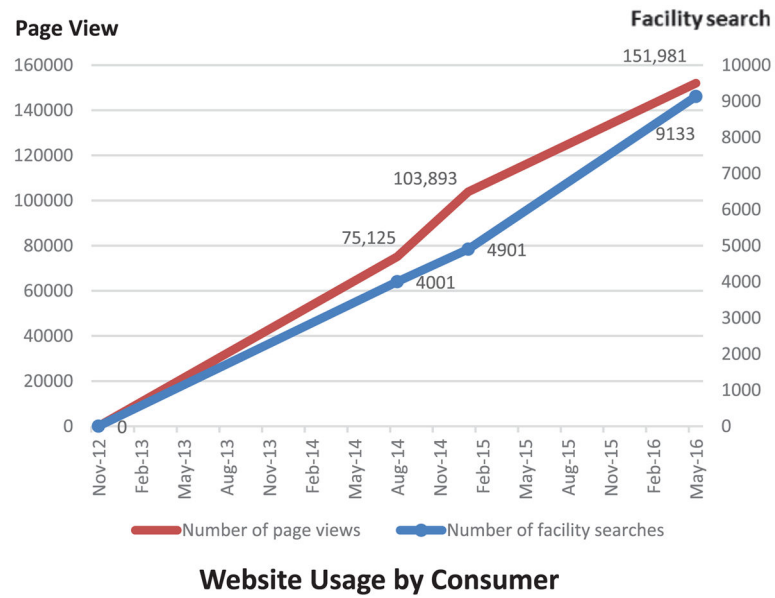


Fig. 3.
Number of page views and facility searches over time.